Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Winter 2010

Future dates

Afternoon meet – Wednesday 23rd February – 4pm
Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ
The hotel, which has plenty of parking, is near the Royal Surrey County Hospital. At the roundabout before the hospital, turn left into the hotel car park. They have a large foyer area with plenty of comfortable sofas and large coffee tables.

Morning meet – Monday 21st March – 11am
Worplesdon Place Hotel, Perry Hill, Worplesdon, Guildford, Surrey, GU3 3RY
There is a wide range of food and drink available (e.g. steak, chicken, fish and lamb grills and salads). This former country house has been fully refurbished in later 2007 to combine its traditional features with more modern facilities. The Hotel offers a large beer garden which features a lake and its own resident duck family.

Evening meet – Tuesday 19th April – 7pm
The Seahorse - 52-54 The Street, Shalford, Guildford, GU4 8BU
Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham).

Food available includes: wood fired pizzas, spit roast chickens, plenty of fresh fish and the finest steaks. Having an excellent chef ensures good food.

XMRV just mouse DNA contamination?

December 21, 2010
Source: www.prohealth.com/library/showarticle.cfm?libid=15810

On Dec 20, the journal Retrovirology published a suite of 4 articles & a commentary(1) essentially giving the impression that studies reporting evidence of XMRV infection in ME/CFS and prostate cancer patient samples is owing to contamination by mouse DNA or RNA, and suggesting “XMRV might not be a genuine human pathogen.” The articles put some reporters into an ‘XMRV is Dead’ mode.

But not so fast !

“What these 5 are doing to the patients is a crime against humanity,” fired back the internationally known Belgian clinician/researcher, Dr. Kenny DeMeirleir. Expect much more research to be published in the first half of 2011 that contradicts their inferences, he promised.

And as for the Whittemore Peterson Institute, which directed the first study finding evidence of XMRV infection in ME/CFS patients, "The coauthors stand by the conclusions of Lombardi et al. Nothing that has been published to date refutes our data," wrote WPI research director Dr. Judy Mikovits in a special statement (attached below).

Specifically, “You will not make an immune response to a lab contaminant,” Dr. Mikovits commented to Wall Street Journal reporter Amy Dockser-Marcus (“XMRV: Raising the Issue of Contamination”).

And as for the Canadian Broadcasting Company (CBC) headline article - "Chronic fatigue [syndrome] study tainted: Scientist" - XMRV Global Action quickly responded, describing it as "a journalistic embarrassment", itself "tainted" by "slothful" failure to conduct any "interviews which capture a balance of credible opinion on the emerging XMRV science."

To see XMRV Global Action's full response with expert quotes and an invitation to use the material in blogs and letters to the media, go to the following link:

http://www.facebook.com/notes/xmrv-global-action/xmrv-global-actions-response-to-the-cbc-news-coverage-of-retrovirology-on-xmrv/486793716796

WPI statement regarding retrovirology article

Dec 20, 2010:
The Lombardi et al.(2) and Lo et al. (3) studies were done using four different methods of detection.

They were not simply PCR experiments, as were the studies by McClure et al. and others who have recently reported their difficulties with contamination.

Experienced researchers such as Mikovits, Lombardi, Lo and their collaborators understand the limitations of PCR technology, especially the possibility of sample contamination.

As a result, we and Lo et al. conducted rigorous studies to prevent and rule out any possibility that the results reported were from contamination.

In addition to the use of PCR methodology, the Lombardi team used two other scientific techniques to determine whether, in fact, we had found new retroviruses in human blood samples.

We identified a human antibody response to a gamma retroviral infection and we demonstrated that live gamma retrovirus isolated from human blood could infect human cells in culture.

These scientific findings cannot be explained by contamination with mouse cells, mouse DNA or XMRV-related virus-contaminated human tumor cells.
No mouse cell lines and none of the human cell lines reported today by Hue et al. to contain XMRV were ever cultured in the WPI lab where our PCR experiments were performed.

Humans cannot make antibodies to viruses related to murine leukemia viruses unless they have been exposed to virus proteins.

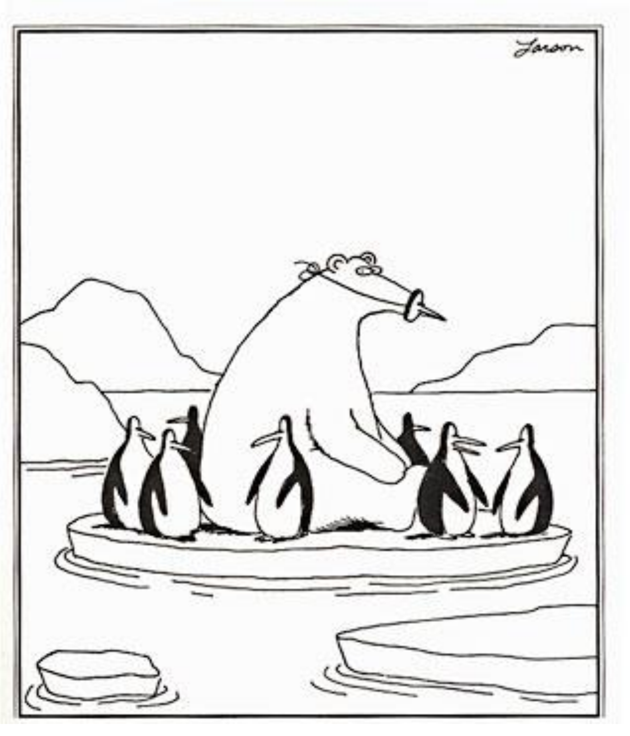
Therefore, recent publications regarding PCR contamination do not change the conclusions of the Lombardi et al. and Lo et al. studies that concluded that patients with ME/CFS are infected with human gammaretroviruses.

We have never claimed that CFS was caused by XMRV, only that CFS patients possess antibodies to XMRV related proteins and harbor infectious XMRV, which integrates into human chromosomes and thus is a human infection of as yet unknown pathogenic potential

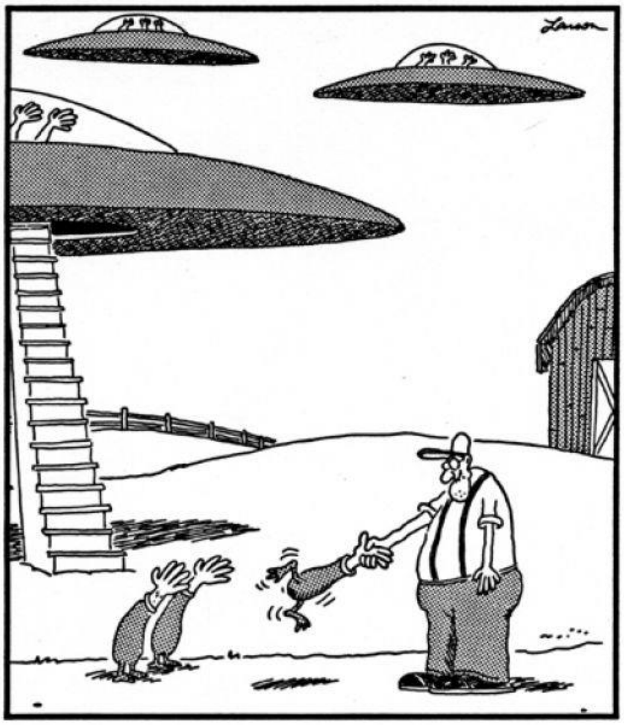
"The coauthors stand by the conclusions of Lombardi et al. Nothing that has been published to date refutes our data."

Judy A. Mikovits

Cartoons



"And now Edgar's gone…Something's going on around here"



Inadvertently, Roy dooms the entire earth to annhihilation when, in an attempt to be friendly, he seizes their leader by the head and shakes vigorously.

Reflexology – comes to you at home

Louise Martin, a recovering ME/CFS sufferer, offers ‘at your home’ reflexology.

Reflexology

Reflexology is a method for activating the healing powers of the body using the reflex areas in the feet that correspond to all the major organs, glands and body parts. I practise a gentle form of reflexology which is excellent for reducing stress and bringing out about deep relaxation whilst helping the body to self-heal.

Being a recovering ME/CFS sufferer myself and having had numerous complementary treatments over the years, I understand the importance of receiving a more gentle treatment which helps to ensure the patient benefits from the therapy given.

Louise Martin

In 2000 I went from healthy and energetic to bed-bound caused by the disabling illness ME. Over the first frightening months I realised that I was embarking on probably the most valuable and challenging lesson of my life, and to recover it would take a strength deep within my spirit that I didn’t yet know I had. Over the years my continuing journey back to health has led me along many healing paths, expanding my knowledge and giving me a valuable insight into the skills and coping mechanisms needed when overcoming chronic illness. As a qualified holistic therapist I am able to offer my expertise and empathy to others, bringing healing, hope and support to those suffering from pain and illness.

Qualifications (Louise Martin VTCT MCThA)

- Reflexology Level 3 VTCT
- Anatomy and Physiology Level 3 VTCT
- Nutrition Advisor Diploma Raworth Centre
- The 'M' Technique Practitioner Diploma
- Health Sciences Certificate The Open University
- Health & Social Care Certificate The Open University
- Qualified First Aider St Johns Ambulance
- Member of Complementary Therapist Association www.complementary.assoc.org.uk
- VTCT Qualified (www.vtct.org.uk)

For more information please email:
info@mobiletherapies.co.uk

or call (after mid-day only)
07989 559694

Dr. Myhill’s right to practice restored

January 7, 2011
Source: www.prohealth.com/library/showarticle.cfm?libid=15848

Following is Dr. Sarah Myhill’s news release of Jan 7, 2011, regarding the reversal and her continuing plan to request High Court action against the GMC. Also, read on to share the final, laughable, charge made against her at her late December Interim Orders Panel (IOP) hearing in all seriousness by GMC prosecutor Gareth Branston.

General Medical Council Restores Doctor’s Right to Practice Medicine
(Press Release Friday, Jan 7, 2011 from Dr. Myhill’s Office)

In a dramatic turnabout yesterday the GMC lifted Dr. Myhill’s suspension and restored her license to practice medicine.

Dr Myhill was jubilant. Her first reaction was to thank her many friends who had stood by her. She said “I am so grateful to those thousands of patients and medical colleagues who knew that I was a good doctor who had done nothing wrong and kept their faith in me. Without their help and support I would have struggled to find the strength to fight.”

The GMC was forced to accept that no patient had been harmed or put at risk of harm and that the reasons they had previously given for Dr Myhill’s suspension had no proper evidence base.

Since her April 2010 Hearing, Dr. Myhill has conducted her own defense without any legal assistance. She pointed out to the GMC at her October, December and January hearings that the GMC had not presented any formal allegations or indeed any case against her - this the GMC is obliged to do by law.

She did not even know if she faced criminal or civil charges.

In the course of her defense Dr. Myhill pointed out to the GMC that it had broken the law with respect to the 1983 Medical Act, the GMC’s own 2004 Fitness to Practice Rules and procedures, the Data Protection Act and the Human Rights Act.

In particular it had abused her right to a Fair Trial, her right to Freedom of Expression and her right not to be punished without due process.

Dr. Myhill was particularly concerned because the GMC had taken patients’ NHS private and confidential medical records without patient knowledge or permission and in breach of the GMC’s own procedures. Furthermore, it used confidential information contained within those notes that it had no right to use.

The GMC initially refused to consider evidence presented by Dr. Myhill, it refused her right to call witnesses, refused to accept facts as facts and refused to accept that the accusing doctors had told lies against her.

The GMC obtained and used documentation improperly, which is in breach of the Data Protection Act, it failed to give her adequate time to prepare her defence, failed to try her within a reasonable time, failed to take basic witness statements from complaining doctors, and accepted the most trivial of complaints to try and bolster their case.
One such example of this was when the GMC upheld the most ridiculous of assertions against Dr. Myhill.

At her December IOP GMC prosecutor Gareth Branston presented Dr Myhill with the following complaint:

“I think finally in the bundle, time-wise, you have an email from a JR to the GMC, which draws the GMC’s attention to an entry that is on the Internet and as I understand it, it is on the Support Dr. Myhill website concerning Dr. Myhill’s assistance with the labour and birth concerning a pregnant family friend.”

If the GMC had bothered to click on the link at the bottom of the Support Dr. Myhill website page they would have seen a picture of her pet pig Rosemary and realized this was a spoof, as the heading “A Christmas ‘Tail’” suggested. [See the story, and photos of "the new mum," Mrs. Rosemary Hogg, the babies, and "proud Dad Jack Hogg," at www.supportdrmyhill.co.uk.]

Indeed, at her hearing yesterday Dr.Myhill wanted to inform the GMC of this error. However, when she tried to, she was prevented from speaking by the Panel. This constituted a further breach of the 1983 Medical Act in which the defendant has the right to be heard.

Dr. Myhill had planned to take the GMC to the High Court in December but this hearing had to be postponed because of the snow. It remains Dr. Myhill’s intention to pursue her High Court action against the GMC on the grounds that it has blatantly infringed and broken the law and its own rules.

As a direct result Dr.Myhill, together with thousands of her patients, has suffered as a result of GMC maladministration.

The GMC has imposed minor administrative sanctions of Dr Myhill’s practice but she expects to get these GMC face-saving gestures lifted at the High Court so she has a completely clean license to practice.

Further information from the Support Dr. Myhill Facebook site www.supportdrmyhill.co.uk
Includes [scroll down through the congratulations]:

- account of Rosemary Hogg’s delivery [Some have asked if she has a facebook account, as they are anxious to 'friend' her. We do not know.]
- transcript of Dec IOP hearing
- yesterday’s GMC determination

The transcript of yesterday’s hearing has yet to be published.

Further information contact 01547 550611
office@doctormyhill.co.uk

ProHealth's founder, ME/CFS patient Rich Carson, sent the following message:

Dear Dr. Myhill:

Congratulations on your recent legal victory. ME/CFS patients throughout the world have benefited from your superb medical care and leading edge advice. The world is a better place because of you, and patients owe you a heart felt thank you.

Needless to say, the medical/legal establishment in the UK owes you a huge apology. What a national embarrassment!

Sincerely,
Rich Carson
Founder, ProHealth

Test yourself for XMRV

The WPI (Whittmore Peterson Institute) has developed a blood test for the detection of XMRV and has an agreement with VIP Dx Lab (Nevada, United States) to license the test.

There is now a WPI licenced test that is available in Europe at ‘RED Laboratories’ in Belgium.

Tests currently offered at RED laboratories

Co-culture

RED Laboratories has licensed the proprietary XMRV test from WP Biotechnologies, a wholly owned subsidiary of the Whittemore Peterson Institute. We use the co-culture procedure, where the sample to be tested is put in contact with an infection-sensitive cell line. XMRV is allowed to replicate in the cells for several days, resulting in significant amplification of viral titers. The amplified virus can then more easily be detected by PCR or Western Blot.

To perform this test we ask 3x 8 ml whole blood in Na-heparin tubes, 1x 2ml yellow cap tube and 2x 2ml whole blood in EDTA tubes. Specimens must be received within 48 hours at room temperature.

Cost of this test is 340€. This price includes the co-culture and a screen for other MLV-related viruses by direct PCR on whole blood.

Serology

RED Laboratories has made an agreement with VIPdx, Reno, Nevada, to offer serology testing. Samples will be collected in our laboratory and sent to VIPdx for analysis.
To perform this test we ask 1x serum separator tube (yellow cap).

Cost of this test is 219€. This price includes first processing of samples (serum separation), storing, shipping to the USA and reporting of results.

Detection of MLV-related viruses by PCR and sequencing

This test is based on the publication by Lo et al., who reported the detection of MLV-related sequences in the blood of CFS patients.

To perform this test we ask 1x 2ml whole blood in EDTA tube (purple cap).
Cost of this test is 108€. Note that it is included in the co-culture test, so you don't have to order MLV screen if you already request co-culture.

We have the capacity to sequence the PCR products, however this is currently performed only for internal use (quality control, research projects). We may start routine sequencing in the future, if it appears that distinguishing the different virus variants is clinically important.

Interpretation of results

Advantages and limitations of each of these tests must be fully understood before drawing any conclusions. In any case interpretation must be done by a physician.

Co-culture

Co-culture is very sensitive and most importantly, is the only test that can distinguish active infections from latent ones. One limitation is the fact that it is performed from blood cells, it may therefore not be able to detect a virus which is present in another part of the body (gut, spleen...). Also, the co-culture procedure has been developed and validated for XMRV. It uses a specific target cell sensitive to XMRV infection. Although it is likely that most virus variants are able to infect this target cell line, this has not yet been demonstrated; therefore there is a possibility that certain viruses (like MLVs) cannot be detected by this technique.

Serology

Serology will be able to detect antibodies, even when the virus is localized in another tissue than blood. It is probably able to detect most variants of XMRV and MLV-related viruses. A major limitation of serology, however, is that it doesn't give any indication regarding the stage of infection. It may also give false negative results, in the case of patients with a deficient immune system, which are unable to make adequate antibodies. In the future, the lack of specificity may also be an issue, if it turns out that variant identification is important for clinical evaluation.

MLV PCR

MLV PCR on whole blood can give very precious information when followed by sequencing, since it allows very precise variant identification. A quantitative PCR test is in development, in order to measure viral titers and not only presence of the virus. PCR can be performed on any type of tissue, including biopsy, saliva, CSF...

A combination of different approaches is probably the best way to test for XMRV and/or MLV-related viruses. A better understanding of XMRV/MLV biology is necessary before we can evaluate with certainty the sensitivity, specificity and clinical relevance of the different approaches used to detect these viruses.

Getting a negative result doesn’t definitely mean that you are not infected. You may be infected with a specific variant not detected by any of these approaches, or the viral titer may be too low at the time of testing.

RED Laboratories does not make any claims regarding the biological significance, and medical implications, of a positive result. Only physicians can do test interpretation, define treatment options, and answer questions regarding transmissibility and health implications.

How to order the test

The XMRV test is "research only" and must be requested and interpreted by a physician (your doctor). An order form must be completed (ensure it is signed and dated) and submitted with the appropriate blood sample and money. Details of the blood sample requirement, shipping instructions and pricing is detailed on the order form.

The order form is available for download from the following website, or can be requested by contacting RED labs using the contact details further below.

www.redlabs.be/red-labs/ordering-tests/request-forms.php

I recommend contacting RED laboratories to fully understand the ordering procedure and pricing.

R.E.D. Laboratories N.V./S.A.
Z.1 Researchpark 100
B-1731 Zellik
Belgium
Phone: +32-(0)2-481-5310
Fax: +32-(0)2-481-5311

VAT/BTW/TVA: BE 462 648 824

Client relation hours: 9 am to 4 pm

Invest in ME
International ME/CFS conference 2011

This will be the sixth annual Invest in ME international biomedical conference on ME/CFS.

The conference will be held on 20th May 2011 in Westminster, London and builds on the successful biomedical research conferences organised by Invest in ME in previous years.

As in previous years Invest in ME aim to raise awareness of the neurological illness myalgic encephalomyelitis (ME/CFS). This conference will highlight the need for a national strategy for biomedical research which will lead to treatment and a cure for this devastating illness - an illness which is 5 times more common in the UK than HIV/AIDS - yet which has had comparatively little funding spent on biomedical research.

Our 2008 conference in London focused on Sub Grouping and Treatments and showed indisputable proof from leading ME/CFS experts regarding the pathology of this illness.
Our 2009 conference concentrated on the severely-affected people with ME.
Our 2010 conference concentrated on the new era of ME/CFS research which had been created by awareness of the XMRV retrovirus.

With the discovery of the xenotropic murine leukemia virus-related virus (XMRV) retrovirus in patients with ME/CFS by the Whittemore-Peterson Institute, the US National Cancer Institute and the Cleveland Clinic of Ohio in 2009 we publicised this major breakthrough in the understanding and treatment of ME/CFS and in the implications in ME/CFS in our 2010 conference.

For 2011 the way forward must be to focus on translational biomedical research into ME/CFS and this means initiating clinical trials using homogeneous patient cohorts and correct clinical guidelines.

Therefore our 2011 conference slogan is:
The Way Forward - A Case for Clinical Trials
and the theme is:
The Need for Guidelines, Treatments and Clinical Trials for ME/CFS

The education of healthcare staff about ME/CFS now needs to break with the past and reflect the new found knowledge about the pathogenesis of ME/CFS which high quality biomedical research is providing.

The conference will be oriented toward providing healthcare staff and others with knowledge of the latest research and the biomarkers which allow appropriate treatments to be prescribed. However, apart from a knowledge of the biomedical research which is ongoing it is necessary for healthcare staff to be aware of the multiple symptoms exhibited by ME patients and of the possible treatments available.

Research data and experiences of treating ME/CFS will be presented as will findings from the latest biomedical research. The time is right for moving ahead with new findings and embarking on clinical trials to enable rapid progress to be made with discovery of effective treatments.
The presenters at the conference represent the world's most current ME/CFS knowledgebase regarding ME/CFS.

The conference provides information and opportunities which are not available via the internet. One of the most important aspects at previous IiME conferences has been the creation or resumption of the unique networking opportunities available with some of the most renowned experts on ME/CFS in the world.

Who should attend?

The conference will appeal to healthcare professionals, doctors, nurses, paediatricians, occupational therapists, researchers, ME/CFS support groups, people with ME/CFS and those working in social services, educational support and the media. The conference provides an opportunity for people within government, health departments, social services and education to be able to be informed of the true nature of ME/CFS and of the current status of diagnosis, treatment and current/future biomedical research possibilities.

Conference registration

Morning and afternoon refreshments, and a hot lunch will be included in the conference price. A small quiet room adjacent to the lecture theatre will be available for some who may wish to rest.The refreshment are available as rest areas during the conference presentations. During lunch and breaks the lecture theatre should also provide a quiet area to sit and relax.Please note this conference is a TICKET-ONLY event - tickets must be purchased prior to the event.

Discounts for early registration and payment are in force until 15th March 2011. The "concessionary patient rate" for people with ME and/or their accompanying or immediate carers is £38 before 15th March, £45 after.

The registration form is available is different ways depending on payment type (cheque, online via credit card) from the following internet link.

www.investinme.org/IiME%20Conference%202011/IIME%202011%20International%20ME%20Conference%20Registration.htm

Which can be found on the Invest in ME website at: www.investinme.org/index.htm

Conference venue

The conference venue is at One Birdcage Walk in the heart of Westminster, London. The conference will be held in the magnificent Lecture Theatre of One Birdcage Walk. The conference will make the day an opportunity to network with other healthcare professionals and patient groups/charities.

Conference speakers

Annette Whittemore

Founder and President of the Whittemore Peterson Institute for Neuroimmune Diseases, Reno, Nevada, USA. The Institute is located on the medical campus of the University of Nevada. Its mission is to serve those with complex neuro-immune diseases such as ME/CFS, viral induced central nervous system dysfunction and fibromyalgia. Annette Whittemore graduated in Elementary and Special Education at the University of Nevada and taught children with neuro-cognitive deficits, such as those found in autism, ADD, and learning disabilities. As the president and director of the current operations at the Institute Annette supports the basic and clinical research program, and actively recruits physicians and other support personnel for the Institute.

Dr. David Bell

Graduated from Harvard College and gained an MD degree at Boston University. Post doctoral training in paediatrics was completed with subspecialty training in Paediatric Behavior and Developmental Disorders. In 1978 he began work at the University of Rochester and then began a private practice in the town of Lyndonville, New York. In 1985 nearly 220 persons became ill with an illness subsequently called chronic fatigue syndrome in the communities surrounding Lyndonville, New York. This illness cluster began a study of the illness which continues today.

Dr. David Bell is the author or co-author of numerous scientific papers on CFS, and, in 2003 was named Chairman of the Advisory Committee for Chronic Fatigue Syndrome of the Department of Health and Human Services. Publications include A Disease of A Thousand Names, (1988) and The Doctor's Guide to Chronic Fatigue Syndrome, (1990). Dr. Bell is currently performing ME/CFS research into the XMRV retrovirus.

Professor De Meirleir
is a world renowned researcher of ME/CFS. He is full professor of physiology, pathophysiology and medicine at the Virje Universitet Brussel and practices Internal Medicine at Himmunitas Foundation also in Brussels. He has published several hundred peer reviewed articles and is co-author of the book 'Chronic Fatigue Syndrome: a biological approach' and was co-editor of the Journal of Chronic Fatigue Syndrome, and reviewer for more than 10 other medical journals.

Professor De Meirleir was one of four international experts on the panel that developed the Canadian Consensus Document for ME/CFS. He assesses/treats thousands of ME/CFS patients annually and is the most experienced researcher in Europe regarding ME/CFS. His research activities in ME/CFS date back to 1990. His other research activities in exercise physiology, metabolism and endocrinology have led to the Solvay Prize and the NATO research award.

(to be confirmed) Professor Olav Mella / Dr Øystein Fluge
Institute of Medicine, Section of Oncology, University of Bergen, Norway
And Department of Oncology and Medical Physics, Haukeland University Hospital, Bergen, Norway

Øystein Fluge received medical degree in 1988 at the University of Bergen, and is a specialist in oncology since 2004. He has worked as a Research Fellow with support from the Norwegian Cancer Society and is now chief physician at the Cancer Department, Haukeland University Hospital. Doctoral work emanates from the Surgical Institute and Department of Molecular Biology, University of Bergen.

See also http://www.biomedcentral.com/1471-2377/9/28

Dr. John Chia
is an infectious disease specialist, Torrance, California, USA. He has published research ("Chronic fatigue syndrome associated with chronic enterovirus infection of the stomach") on the role of enteroviruses in the aetiology of ME/CFS - an area which has been implicated as one of the causes by a number of studies. There are more than 70 different types of enteroviruses that can affect the central nervous system, heart and muscles, all of which is consistent with the symptoms of ME/CFS. By analyzing samples of stomach tissue from 165 patients with CFS, Dr. Chia's team discovered that 82% of these individuals had high levels of enteroviruses in their digestive systems. Dr Chia's research may result in the development of antiviral drugs to treat the debilitating symptoms of ME/CFS.

Dr.Judy Mikovits
is Research Director at the Whittemore Peterson Institute for Neuro-Immune Diseases and has co-authored over 40 peer reviewed publications that address fundamental issues of viral pathogenesis, hematopoiesis and cytokine biology. Formally trained as a cell biologist, molecular biologist and virologist, Dr. Mikovits has studied the immune response to retroviruses and herpes viruses including HIV, SIV, HTLVI, HERV, HHV6 and HHV8 with a special emphasis on virus host cell interactions in cells of the hematopoietic system including hematopoietic stem cells (HSC).

Dr Mikovits is one of the authors of the ground-breaking study published in Science magazine in October 2009 which detected XMRV in CFS patients (Detection of an infectious retrovirus, XMRV, in blood cells of patients with chronic fatigue syndrome) and is a member of the US Department of Health and Human Services Blood Working Group.

Professor Malcolm Hooper
Chair of the 6th Invest in ME International ME/CFS Conference 2011 will be Professor Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, University of Sunderland.

Professor Hooper is an internationally-renowned expert on ME/CFS and a tireless campaigner for patients' rights. Professor Hooper has previously chaired Invest in ME conferences and participates in "Invest in ME Hooper Interviews" - interviews with conference speakers at the Invest in ME Conferences which appear on the resultant conference DVDs.

Adverts

The following adverts have come into our group email and have asked to be included in our newsletter.

Expert Patients Programme Online

is a free six-week self-management course for people living with long-term health conditions or disabilities. The course has had good reports from people living with ME/CFS and Fibromyalgia. Participants join a small online group which all begin the programme at the same time, then they access the course over the six weeks looking at topics such as managing tiredness and pain, coping with feelings of depression, relaxation techniques, healthy eating, action planning and problem solving and communication skills.

Each participant is given a user name and is able to interact safely with other participants through discussion boards as people move through the topics, but rather than missing a week if your health dips there is the flexibility of logging on within each week at a time that suits you.

If you are interested in getting more information or booking a place please call our freephone number: 0800 988 5520 to talk to one of our team. All places are FREE!

Experiences of chronic illness, voices from England and Portugal

Study About Chronic Illness at Lancaster University invites people with Multiple Sclerosis (MS), Fibromyalgia, Myalgic Encephalopathy (ME) and Chronic Fatigue Syndrome (CFS) who live in England and Portugal to share their experiences.

LANCASTER
UNIVERSITY

Please visit ChronicIllnessStudy.com for more information and to take part. This study about chronic illness forms part of a PhD thesis by Ana Bê Pereira at Lancaster University.

Ana wants to know more about the everyday experiences of people who have chronic illnesses. Ana wants to find out if people who have chronic illnesses (specifically MS and ME/Fibromyalgia/CFS) experience discrimination or disadvantages of any kind and, if so, how this occurs in their lives. She also wants to find out what kind of things people might do daily that help them go about their lives, despite their illness, as well as any new ways of doing things that people learned since having the illness. These might be things that people decide to do themselves, or learn from other people in similar situations.

Ana invites people who live in England and Portugal to tell her their experiences, in their own words, by submitting their ‘spoken’ or ‘written’ accounts to her in a safe way, via a website created for this purpose only.

If you would like more information about this study or if you would like to tell Ana about your experiences, please visit the website ChronicIllnessStudy.com and send your experiences, either written or recorded, through the website. You will find all necessary information on the website. Everything you say will be sent securely directly to Ana and your privacy will always be protected. The things you say will NEVER appear on the website.

If you have any questions, please contact Ana via email: a.pereira@lancaster.ac.uk